

care will be required to assist those disabled children with complicated or life-threatening conditions, or who require highly specialized tertiary care.

#### *4. Improve Financing of Care*

The service system must adequately compensate providers and consumers using out-of-hospital facilities which are close to the patients' home community and which meet established care standards. Funding mechanisms must also be made available for expensive out-of-hospital technical equipment that reduces the length of hospital stays. Planning and coordination of community services for complicated and serious disabilities must be recognized as a legitimate reimbursable expense.

#### *5. Identify Areas of Abuse Potential*

Actions and inactions can both contribute to abuse of the care system for the disabled child. Elimination of unnecessary, duplicated or inappropriate services assure quality care and control costs. Standards and regulations must be developed and monitored by qualified professionals familiar with the service delivery issues. Methods to provide parents and providers with information or optimal services for children with disabilities must be an essential part of the regionalized system.

#### *6. Incorporate into Training Curricula Principles of Care For Children with Disabilities*

There is a need for the incorporation of clinical experiences relating to the care of disabled infants, children, and young adults into all levels of pre-service and in-service education for health professionals. Utilization of interdisciplinary methods in the training process encourages coordinated clinical care. Teaching models should enhance professional satisfaction in caring for disabled children. Methods to improve communication skills among patients, parents, and fellow workers must be inherent components of the training program.

#### *7. Support Research in the Care of Children with Disabilities*

While our scientific understanding of specific disabling diseases and conditions is sophisticated, a great need remains to learn more about optimal methods of health care provision for disabled children. Research should include investigations into a) curricular revisions to better train professionals in evaluatory methods and treatment techniques; b) methods to enhance communication and coordinating skills; c) procedures to improve financial reimbursement procedures; d) methods to promote intra- and interagency understanding; and e) methods to immediately disseminate new information concerning the care of disabled children. Increasing concern for fiscal responsibility and accountability will dictate the wisdom of devoting significant portions of available resources to expand research and development endeavors.



## SUMMARY OF THE WORKSHOP

In the summer of 1982, Surgeon General C. Everett Koop, M.D. requested that a Workshop on Children with Handicaps and their Families be convened to seek out ways to lessen the handicaps imposed on disabled children and to promote child and family self-sufficiency and autonomy. The workshop was held at The Children's Hospital of Philadelphia on December 13 and 14, 1982. Over 150 individuals, including handicapped patients, their families and those involved with their care, were invited to participate in the conference. An additional 100 people attended parts of the proceedings because of their interest in the welfare of handicapped children. All of the participants paid their own expenses or were supported by their own institutions. Financial assistance was provided for participating patients and parents.

The Workshop was called in response to the revolutionary transformations in medical technology which have taken place during the past four decades. Discoveries and applications in the fields of antibiotics and other drugs, in vaccines, in computerized imaging procedures, in life-support and monitoring, in laboratory techniques, and in the understanding of basic physiology have altered the prognosis for innumerable children. The baby who is born premature, the infant with severe congenital defects of the major organs or skeleton, and the child who is damaged by severe trauma or infection can now be supported by the combination of high technology and trained medical personnel. Many of these children now survive, and most of those who do can look forward to a productive life, though often impeded by residual disability.

Modern American society has geared itself to almost unlimited support of this technology. But support for the essential services systems outside the tertiary care environment has not kept pace for the increasing numbers of children whose lives are being saved. Technology is expensive, essential support services are also expensive, and funds are limited. Numbers of questions require consideration. Can we maintain the technological support, yet improve the essential services with the funds available? Do we need more funds? Can we find ways of redistributing the funds now being spent? Can we devise strategies for providing more humane service with fewer dollars?

Those attending the workshop concentrated on the severe, specific problems of the ventilator-dependent child, and the findings for this prototype were extrapolated for their implications for all handicapped children.

Dr. Robert G. Kettrick, Chairman of the Workshop, challenged the audience to accept responsibility for insuring that all reasonable care alternatives be made available for ventilator-dependent children. He asked them to identify and correct the circumstances which prevent transfer from an acute facility to home or community alternatives and presented a number of illustrated case histories representative of the progress which can be achieved by a child on home care.

Presentations of programs in Illinois, New York, and Pennsylvania explored problems and progress in meeting the needs of increasing numbers of ventilator-dependent children. A parent, Mrs. Betty Wartenberg, presented a summary of the life of her nine-year-old son. She gave an account that recalled the years on ventilator support in an intensive care unit, the disruptions to family unity, and of the remarkable progress made after his transfer to home care.

Following these presentations the participants were assigned to working groups where a mix of disciplines were used to assure an interchange of ideas and perspectives. Parents met insurance people, government executives saw and talked with handicapped patients who were in wheelchairs and on ventilators, executives of service organizations walked the acute and intermediate wards of the hospital and interacted with children who have lived there all their lives—3 or 4 years; legislative aides participated with physicians and hospital administrators. During this brief time a mechanism evolved which cut through the intermediaries of typed letters, impersonal phone calls, and layers of formalization. A consensus of the working groups' deliberations was reported to a final plenary session, which marked the close of the workshop.

## SYNTHESIS OF THE DELIBERATIONS AND THE SURGEON GENERAL'S RESPONSE

The summaries and recommendations of the workshop groups reveal an overwhelming diversity of concepts and directions to be considered. Many ideas arose repeatedly during the two days of discussion and can be grouped within broad categories:

- Developing regional systems of care
- Defining the scope of the problem
- Developing model standards for quality assurance
- Incorporating principles of care for children with disabilities into current education curricula
- Identifying areas of potential abuse
- Supporting research on the care of children with handicaps
- Improving financing of the kinds of care these children and their families need

While the workshop did not focus specifically on ethical matters, the effect of each participant's set of social values was always apparent during discussions. Interaction was influenced by each person's values, conscious or not, stated or unstated. Throughout the process one quality—humaneness—permeated all. Humaneness, thus, was a common thread and a universal motivation. Every expression of thought seemed to emanate from the theme, "What is best for the child?"

In declaring the Workshop a success and accepting its recommendations, the Surgeon General praised the participants for their efforts and expressed his belief that the eventual outcome will be better health care for a more diverse group of children with disabilities. In his closing remarks, Dr. Koop assured the participants:

- That funds would be available for a small number of demonstration projects to develop the structure of a regionalized system;
- That a study of the national prevalence of ventilator-dependent children would be encouraged;
- That professional organizations would be encouraged to develop model standards for care;
- That public and private institutions will be encouraged to incorporate principles of care for ventilator-dependent children into their curricula;
- That abuses of resources will be identified and corrected;
- That those public and private agencies which fund research will be made aware of the issues presented at the Workshop; and
- That a primary focus of the federally-funded demonstration projects would be the issue of cost reimbursement from public, private, and voluntary sources; cost-reimbursement issues would continue to be discussed with insurers.

“Where we have it in our power, we hope to make their handicaps temporary, or, at least to ameliorate their severity. We will be using a variety of techniques to continue the momentum which has developed at the Workshop, and I will report back to you as we make progress on the various suggestions you have passed on to me as Surgeon General.”

“The Department of Health and Human Services has a very strong commitment to improve services to disabled children and their families. And, as long as I am Surgeon General, disabled children have a very strong advocate in the Public Health Service.”

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# APPENDIX C

## PROTOTYPE HOME PROGRAM REVIEW FOR VENTILATOR-DEPENDENT CHILDREN

The Children's Hospital of Philadelphia

### I. GOALS

- To provide safe respiratory support within the home environment
- To resolve problems of cash flow for payment of services

### II. INITIAL STAGE

#### A. Service Provision

- Consultation with institutions planning home care for the ventilator-dependent child
- Supervision of respiratory care of program participants
- Home visits by health care team
- Telephone access to health care team
- Referral to appropriate service agencies
- Coordination of inter-agency and family contract
- Development of resource list
- Development of parents' support group
- Coordination of consultative services, i.e., nutrition, respiratory therapy, rehabilitation, etc.
- Classification of nursing needs for third party payers
- Crisis intervention
- Supportive counseling (i.e., bereavement, effects of chronic illness on siblings, etc.)
- Liaison between Commonwealth of Pennsylvania—Department of Health and Welfare and families
- Liaison with vendors
- Disbursement of Commonwealth of Pennsylvania—Department of Health and Welfare funds in order to meet legislative intent of *Appropriation Act 17A of 1980*

#### B. Educational Services

- Development and supervision of family and home care-givers pre-discharge training program
- Provision of post-discharge parent education
- Education for parent advocacy
- Education for parent assertiveness
- Education of health professionals regarding home-care for ventilator-dependent children
- Liaison between families and school districts

- C. Documentation and Investigation Needs
  - Patient classification of nursing care needs
  - Nursing assessment
  - Developmental assessment
  - Parents' Guide for Home Care
  - Interview guide for parents when hiring home-care givers
  - Nutritional assessment
  - Pre-discharge Social Work Protocol
  - Post-discharge Social Work Protocol
  - Individual Service Plan
  - Patient population survey
  - Resource list for parents and professionals
  - Documentation of program costs for ventilator-dependent children
  - Documentation of family costs for the care of a ventilator-dependent child
- D. Policy Guideline and Procedure Development
  - Eligibility review
  - Enrollment criteria
  - Equipment and supply lists
  - Motor vehicle accessory lists
  - Purchase agreements for equipment
  - Acquisition of capital equipment
  - Reimbursement for electricity bills

### III. SECONDARY STAGE

- A. Service Provision
  - Consultation with institutions planning home care for ventilator-dependent child
  - Provision of nutrition consultant
  - Provision of a home visit by a member of the home health care team at least annually
  - 24-hour 7-day-a-week telephone access to medical personnel
  - Education of parents about community service agencies and their services
  - Provision of a forum for peer support
  - Provision of and payment for services of home care personnel, i.e., nurses, respiratory therapists
  - Provision of an objective analysis of nursing care needs for prescriptions and negotiation with third-party payers
  - Exploration of resources for crisis intervention
  - Exploration of local resources for supportive counseling
  - Provision of library resource or bibliography on chronic illness and related effects
  - Provision of expertise and cash flow to families for acquisition of capital equipment, disposable and non-disposable supplies for health care and rehabilitation needs
  - Resolution of cash-flow dilemma
  - Provision of payment for necessary care not reimbursable by established third-party mechanisms

- Liaison with third-party payers to investigate and consider cost-effectiveness of home care vs. long-term institutionalization
- B. Educational Services**
- Development of instruction manual for hospital use in educating and testing families in home health care of ventilator- and/or oxygen-dependent children
  - Development of a parent organization
  - Development of continuing education programs for health professionals involved in care of ventilator-dependent children
  - Proper placement within an educational system
- C. Documentation and Investigation Needs**
- Resolution of conflict between families and third-party payers relative to appropriateness of nursing care
  - Documentation of nursing needs
  - Development of program for acquiring comprehensive nursing data base
  - Documentation of developmental profiles
  - Provision of hospital-based education to insure comprehensive education of families who will care for ventilator-dependent children
  - Documentation of nutritional status and interventions
  - Development of protocol for social workers who may be involved in discharge planning of ventilator-dependent children
  - Development of a protocol for social workers involved in the home care of ventilator-dependent children
  - Development of individual service plans for all children within the program
  - Definition of the number of acute-care institutions currently involved in the care of ventilator-dependent children
  - Development of family financial profiles
  - Documentation of medical and social services not being met by third-party payers
  - Definition of services mandated by existing State and Federal programs
- D. Policy and Procedure Development**
- Development of policies and procedures to provide uniform services to families enrolled in program
- E. Contingency Planning**
- Development of contingency plans to help families to deal with termination of money
- IV. FINAL STAGE**
- A. Service Provision**
- Institutionalize a program within the Commonwealth of Pennsylvania, Department of Health and Welfare to insure that the needs of ventilator- and/or oxygen-dependent children and their families are met

**B. Educational Services**

- Provide or insure access to an educational system as provided for by the Commonwealth of Pennsylvania and Federal Law (PL 94-142 and Rehabilitation Act of 1973 Section 504)
- Provide a comprehensive education program for professionals involved in the care of ventilator-dependent children
- Define a comprehensive continuing education program for families of ventilator-dependent children

**C. Documentation and Investigation Needs**

- Develop and prepare standards of care, costs, policies and procedures for the care of ventilator-dependent children
- Investigate and document advantages and disadvantages of disposition alternatives for ventilator-dependent children
- Investigate and document the effect of a ventilator-dependent child on family functioning

# APPENDIX D

## SELECTED READINGS

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